

Clinical Standards Adult Renal Services

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1

1 Introduction

This document introduces the Clinical Standards Board for Scotland's (CSBS's) *Clinical Standards for Adult Renal Services*. These standards will be used by the Clinical Standards Board for Scotland (the Board) to assess the quality of clinical services provided in hospital settings throughout Scotland for people with renal disease, with a particular focus on chronic renal failure, as this represents the vast majority of the workload in renal units.

The document begins with some background information on the Board and on the standards it is developing (Sections 2 and 3, respectively).

The process by which the *Clinical Standards for Adult Renal Services* were developed is then described (Section 4) and the membership of the Renal Services Project Group, responsible for the development of the standards, is presented (Section 5). A context for the standards is given by way of some overarching principles (Section 6).

The next part of the document (Section 7) entitled 'An Introduction to Renal Disease (Including Renal Failure)' defines the terms used throughout the standards and summarises what is meant by renal disease; principally for the benefit of readers who are not healthcare professionals.

A more scientific assessment of the evidence underpinning the standards is presented in Evidence Base for the Clinical Standards for Adult Renal Services (Section 8). This information provides a further level of detail than is given in the standards, with regard to current research.

The Clinical Standards for Adult Renal Services can be found in Section 9.

A Glossary of Terms covering the main items detailed in the standards can be found in Section 10.

2 Background on the Clinical Standards Board for Scotland (CSBS)

The CSBS was established as a special NHS Board in April 1999.

The Board's task is to develop and run a national system of quality assurance and accreditation of clinical services, with the aim of promoting public confidence in NHSScotland.

The Board has adopted the following definitions:

Clinical Service

In some cases, this means looking at the services provided for people with a particular condition or diagnosis (eg ovarian cancer), in other cases, at those services relating to a range of manifestations (eg kidney diseases).

Quality Assurance

Improving performance and preventing problems through planned and systematic activities including documentation, training and review.

Accreditation

A process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.

Project Groups

For each service in the accreditation programme, the Board appoints a project group comprising appropriate healthcare professionals and lay people to oversee the accreditation process: developing and consulting on the standards; managing external peer review; and reporting conclusions to the Board.

As part of its rolling programme, individual project groups ensure the standards are regularly evaluated and revised to ensure that they remain relevant and up-to-date (reflecting new procedures and treatments), and that targets of achievement are driven up as performance improves.

Development of Standards

Groups working on behalf of the Board to develop standards are expected to:

- adopt an open and inclusive process involving a wide range of both lay and professional people through a variety of mechanisms;
- work within the Board's policies and procedures as set out in the Quality Assurance & Accreditation Manual (August 2000);
- test standards through undertaking pilot reviews to ensure that they meet the principles of the Board.

In addition to standards for specific services or conditions, the Board has set generic standards which apply to all clinical services; more detail on the generic standards is provided in Section 3.

Accreditation Process

The framework for the Board's accreditation process is as follows:

- once the standards have been finalised, each relevant Trust is asked to undertake a self-assessment exercise for their service against the standards;
- a review team visits the Trust on behalf of the Board and follows up this selfassessment exercise with an external peer review of performance in relation to the standards;
- the Board reports the findings for the Trust, based on the self-assessment exercise and on the external peer review.

Peer review teams are multidisciplinary, including both healthcare professionals and members of the public. All teams are led by an experienced clinician and are supported by staff from the Board.

All the processes that the Board is developing are subject to review and evaluation, and this will help the Board improve its system of quality assurance and accreditation. In particular, all its initial projects are, in effect, pilots designed to test the rigour and appropriateness of the Board's approach as well as to assess performance of NHSScotland against the standards that have been set.

Further Information

Further details on the process by which the Board will achieve its objectives can be found in its *Quality Assurance & Accreditation Manual* (August 2000). Copies of this manual are available from:

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For further information about the Board and to obtain additional copies of the standards, please visit the Board's website: www.clinicalstandards.org

3 Background on Clinical Standards – Basic Principles

Principles Applicable to all Clinical Standards

The following basic principles apply to all the Board's standards:

- they are written in **simple language** that is easily understood by lay people and by healthcare staff at all levels;
- they are **evidence-based**, recognising that levels and types of evidence vary and include evidence relating to patients' experiences;
- they are, wherever possible, based upon and consistent with other recognised standards, for example, guidelines produced by the Scottish Intercollegiate Guidelines Network (SIGN) and equivalent organisations, and national audits;
- they are explicit and measurable yet realistic;
- they are **mandatory** in that no profession can 'opt out' and they apply to all parts of NHSScotland;
- they are **results oriented** in terms of improved **outcomes for patients**. While many relate to **process** (healthcare practices, treatments and interventions) and some to **structure** (eg staff numbers and qualifications, buildings, equipment and organisational arrangements), these require to be linked through evidence to outcomes;
- they are credible and widely disseminated;
- they are **few in number**, focusing on what really is important in delivering high-quality care and treatment; and
- when taken together, they form a **balanced** set so that focus on their achievement does not distort effective holistic care and treatment.

The standards that the Board develops are related to the **patient's journey** through different parts of NHSScotland. This reinforces their patient focus and highlights the links between primary, community and hospital services and between the work of all the healthcare professionals involved in the provision of each service.

The Board's role of supporting healthcare professionals in driving standards upwards will be furthered only if standards are within the realistic reach of most parts of NHSScotland. The challenge, therefore, is to set standards that are 'achievable but stretching', and to produce reports identifying areas where such standards are being met or exceeded as well as those where they are not being achieved, so that the latter can learn from the former.

Generic Standards

In addition to condition-specific standards such as those set out in this document, the Board has developed generic standards which apply to clinical services generally.

These generic standards are grouped under two broad headings:

Patient Focus

These are designed to ensure that "all services respond to patients' needs and preferences, and that patients are involved in decisions about their own care through effective two-way communication and information-sharing", and cover:

assessment

The initial assessment helps staff determine the care that each patient needs and prefers, and requires the collection of information and the development of a plan of care in response.

patient involvement

Patient care outcomes are improved when patients and, as appropriate, their carers, are involved in clinical care decisions.

- patient information

Information helps patients make informed choices, which can reduce anxiety and encourage participation in recommended treatment.

- patient/staff communication

Good communication between patients and healthcare professionals is essential for effective individual treatment and patient well-being. Poor communication can lead to less effective diagnosis or reduced compliance with treatment, and can create anxiety, distress and dissatisfaction.

patient feedback

Encouraging patients/carers to make comments, suggestions and complaints about the organisation's services allows the organisation to gain a patient's perspective to inform the review and development of services.

access to services

Patients should have access to the services of the healthcare organisation based upon identified healthcare needs and individual preferences.

discharge arrangements

Effective discharge planning begins on, or shortly after, admission and is a continual process. Communication and transfer of information among healthcare professions is essential to a seamless process.

Safe and Effective Clinical Care

These are designed to ensure that "all patients receive safe and effective care and treatment based on available evidence", and cover:

clinical guidelines

Care delivered in accordance with clinical guidelines produces better outcomes for patients.

clinical audit

The review of clinical practice through audit is a well-established means of promoting the quality of clinical care by identifying shortfalls in performance against standards and best practice.

risk management

The management of risk results in a safer system of work, safe practices and an enhanced awareness of possible risk areas.

risk environment

Healthcare organisations work to reduce and control hazards and risk, prevent injury, and generally, to maintain a safe, functional environment for all patients and staff.

staff

A healthcare organisation requires appropriately qualified staff to meet the needs of the patients it serves. Review of individual competencies and continuing professional development are essential.

As with all the condition-specific standards, the generic standards are available on the Board's website (www.clinicalstandards.org).

The Board will use the generic standards in two complementary ways:

- As a 'prompt' during its condition-specific reviews, picking up issues that are
 particularly important in relation to the service under review or on which a
 dialogue with the Trust under review seems appropriate.
- 2. To conduct a baseline review of performance against the generic standards in each NHS Trust and Island Health Board.

To avoid duplication, the issues covered by the generic standards are mentioned in the condition-specific documents only when the relevant project group concludes that there is an additional dimension warranting inclusion. Trusts will be alerted in advance to any other generic issues that the review team wishes to raise during the visit.

Format of Standards and Definition of Terminology

All standards set by the Board follow the same format:

- Each standard has a **title**, which summarises the area on which that standard focuses.
- This is followed by the **standard statement**, which explains the level of performance to be achieved.
- The **rationale** section provides the reasons why the standard is considered to be important.
- The standard statement is fleshed out in the section headed **criteria**, where it states exactly what must be achieved for the standard to be reached.

As already explained, the Board aims to set standards that are **achievable but stretching**. This is reflected in the criteria. Most criteria are **essential** in that it is expected that they will be met wherever a service is provided. A few criteria are **desirable** in that they are being met in some parts of the service, and demonstrate levels of quality which other providers of a similar service should strive to achieve. Each project group is responsible for determining which criteria are essential and which are desirable.

The criteria are numbered, for the sole reason of making the document easier to work with, particularly for the assessment process. The numbering of the criteria is not a reflection of priority. The distinction between essential and desirable is the only way in which criteria have been prioritised.

These standards are also available on the CSBS's website (www.clinicalstandards.org).

4 Development of the Clinical Standards for Adult Renal Services

Background

The Standards for Adult Renal Services are the result of collaboration between the CSBS and the Scottish Renal Registry. The role of the Scottish Renal Registry is to collect and audit data on all patients who are on renal replacement therapy (RRT) across Scotland. The aim is to promote the improvement of renal services for this group of people.

Founded in 1990 by the Scottish Renal Association with a grant from the Clinical Resource and Audit Group (CRAG), the first task of the Scottish Renal Registry was to record details of all patients on RRT throughout Scotland. Once a system of computerised data collection was operational, the Scottish Renal Registry moved into comparative audit between renal units. This focused on aspects of the quality of care of patients on RRT. The Registry is now able to audit most of the standards developed by the UK Renal Association.

The Renal Association is the professional body for UK nephrologists. It has developed standards for the treatment of adult patients with renal failure. First published in April 1995, a third edition of the standards has been published in 2002. Standards of care have also been published by the British Transplantation Society.

It was recognised that not all aspects of quality of patient care could be addressed by audit of biochemical and haematological data. In 1998, further funding from CRAG allowed the Scottish Renal Registry to carry out multidisciplinary peer review visits, including patient representation, to all renal units in Scotland. In order to identify patient priorities for quality of care, meetings were held with representatives of the Kidney Patients' Associations in Scotland. The visiting team reviewed how well a renal unit met the Renal Association standards in addition to the requirements of the Patient Associations. Feedback meetings were held after every two to three visits to discuss ways of improving the process. A report with comments and recommendations was sent to the renal unit and to the relevant Trust and Health Board. By May 2001, the Scottish Renal Registry had completed the first phase of review visits to all adult units in Scotland.

There was potential for overlap between the work of the Scottish Renal Registry and the role of the CSBS in developing standards and carrying out peer review visits. Following discussions between the two organisations it was agreed to work together to develop national Clinical Standards for Adult Renal Services.

Using these standards, 'Phase 2' of the peer review programme will be run with health professionals and lay people. To take this forward a Project Group comprising both health professionals and members of the public was set up to draft the standards. In the development of the standards the Project Group has drawn on the work already undertaken by organisations such as the Scottish Renal Registry, the Renal Association and the Kidney Alliance.

Subsequent to the publication of these *Clinical Standards for Adult Renal Services*, the CSBS will assess the performance of services throughout Scotland in relation to these standards. The Renal Services Project Group will oversee this assessment procedure.

5 Membership of the Renal Services Project Group

The membership of the Renal Services Project Group, chaired by Dr Brian Junor, Consultant Nephrologist, Western Infirmary, Glasgow, is presented below:

Name	Title	Health Board Area
Mr Murat Akyol	Consultant Transplant Surgeon	Lothian
Mrs Caroline Arnott	Ward Manager	Fife
Dr Gordon Baird	General Practitioner	Dumfries & Galloway
Mrs Barbara-Jane Barton	Administrative Assistant, Scottish Renal Registry	Greater Glasgow
Mrs Megan Casserly	Patient Representative	Greater Glasgow
Mrs Rhona Duncan	Renal Dietician	Ayrshire & Arran
Mr James Dunleavy	Renal Pharmacist	Lanarkshire
Mr Sandy Glass	Health Council Representative	Highland
Dr Chris Isles	Consultant Physician/Nephrologist	Dumfries & Galloway
Dr Brian Junor	Consultant Nephrologist	Greater Glasgow
Ms Lesley Logan	Operations Manager, Renal, Transplant and Vascular Directorate	Lothian
Professor Alison MacLeod	Honorary Consultant Physician/ Nephrologist and Chair of Renal Association Standards Group	Grampian
Mrs Maureen Perry	Research Nurse	Tayside
Dr Keith Simpson	Consultant Physician and Chair of Scottish Renal Registry	Greater Glasgow

The Board member specifically working with the Renal Service Project Group is Professor John Cromarty, Trust Chief Pharmacist, Highland Acute Hospitals NHS Trust.

Dr David Steel, Chief Executive, Mr Sean Doherty, Review Team Manager and Miss Fiona Dymitrenko, Project Officer provided support from CSBS.

6 Overarching Principles

As explained in Section 3, the CSBS has set generic standards, which are standards of care that underpin all clinical services provided by NHSScotland. They provide a broader context for all of the Board's condition-specific standards and should be read in conjunction with these standards.

Overarching principles were developed covering the *Clinical Standards for Adult Renal Services* as follows:

- The standards are evidence-based and have been developed and finalised in
 consultation with many people across Scotland. They should represent what
 are considered to be the key elements of care and treatment for people with
 renal disease, particularly those with end stage renal failure.
- Within this phase of standard setting for Adult Renal Services, the Project
 Group agreed to concentrate on chronic renal failure, with reference, where
 applicable, to acute renal failure. Care of patients with chronic renal failure
 who receive renal replacement therapy represents the largest element of the
 workload of renal units. In addition, the treatment given to this group of
 patients can act as a surrogate marker for the quality of care given to all
 patients with renal disease.
- Treatment for chronic renal failure is lifelong.
- The need for multidisciplinary team working across disciplines is emphasised in the generic standards and reflected throughout the Clinical Standards for Adult Renal Services.

The Project Group also identified a number of key points which should be noted in order to interpret and apply the standards for Adult Renal Services, namely:

- The Group recognised the large proportion of patients who develop chronic renal failure as a result of diabetes. Reference should be made to Standard 9 of the *Clinical Standards for Diabetes*, which addresses the assessment, treatment and referral of diabetic patients with renal problems. Copies can be obtained from the CSBS or via the CSBS website (www.clinicalstandards.org).
- A problem encountered in relation to a number of the standards was to set the specific percentage of patients who should achieve a target, eg Standard 4-85% of patients should achieve a haemoglobin of no less than 10g/dl. This does not mean that a unit should not be striving to achieve the set target in all patients, but is an acceptance of the fact that at any one time clinical and other problems will mean that this set target cannot be achieved in all cases.

- The Group acknowledged the importance to patients of issues surrounding travelling times for haemodialysis, and gave much consideration to them. However, without comparative data and sufficient evidence, it was decided that at this stage it was not possible to set a measurable criterion in this area.
- The CSBS Project Group has drawn on the third edition of the Renal Association publication, *Treatment of Adults and Children with Renal Failure Standards and Audit Measures*, 3rd Edition Royal College of Physicians London and Renal Association 2002, in order to maintain consistency in the standards. There is also joint membership between the Project Group and the Standards and Audit Committee of the Renal Association to facilitate this process.

7 An Introduction to Renal Disease (Including Renal Failure)

Basic Facts About Renal Disease

Renal disease (or kidney disease) is a condition that occurs when the kidneys stop working properly.

Most people are born with two kidneys. Healthy kidneys have several important roles. Firstly they clean the blood of waste and excess water. The food and drink we consume provide the body with the nutrients it needs for energy, growth and repair. After the body has absorbed what it needs, it must get rid of what is left over (the waste and excess water). As the blood passes through the kidneys, small filters, called nephrons, remove the waste and excess water, which then become urine. This filtering process also allows the kidneys to maintain the correct balance of chemicals, salts and acid in the body. Finally, the kidneys produce three hormones, which stimulate the making of red blood cells, control blood pressure and maintain calcium levels in the body.

When the kidneys stop working properly, the waste substances and fluid build up in the blood and damage the body. The kidneys also stop producing hormones, which leads to anaemia, high blood pressure and the bones weakening.

Types of Renal Disease

Acute Renal Failure occurs when the kidneys suddenly stop working properly. There are a number of causes including infection, a sudden loss of blood, injury to the kidney or even some medicines or poisons. A person with acute renal failure will often recover totally after a short time of treatment. It may be treated by diet, medication or dialysis. Occasionally the kidneys do not recover and the patient may progress to chronic or end stage renal failure.

Chronic Renal Failure is when a person's kidneys gradually stop working properly. It is often caused by diabetes or glomerulonephritis. Chronic renal failure cannot be cured. It is a lifelong condition that requires more treatment as it progresses, and has a severe impact on a person's life. In the early stages, progress of the disease may be slowed through diet and medication, but eventually it progresses to end stage renal failure.

End Stage Renal Failure is the final stage of renal disease when there is total and permanent kidney failure. A person with end stage renal failure will die within weeks or months unless they receive renal replacement therapy (dialysis or kidney transplantation).

The Symptoms of Renal Failure

Most kidney diseases develop slowly and at first there may be no obvious symptoms. The first signs of kidney disease are very general: frequent headaches, tiredness and itching. As the disease progresses some people may need to go to the toilet more frequently, lose their appetite or experience sickness and vomiting. Some people also suffer from swollen ankles, develop high blood pressure and have trouble concentrating.

A person with renal disease may experience all or only some of these symptoms.

Causes of Renal Disease

Many chronic renal diseases damage the nephrons (filters) in the kidneys. They therefore lose their ability to filter wastes and excess fluid. There are many conditions that can lead to renal disease, the most common being diabetes, glomerulonephritis, genetic disorders (such as polycystic kidney disease) and high blood pressure. Although renal disease can occur at any age, the risks increase with age.

Testing for Renal Disease

Renal disease is usually tested using blood and urine samples, which show whether there are abnormal levels of certain substances in the blood or urine. Further tests are then done using various imaging methods, such as ultrasound or computed tomography scan (CT scan). These methods take pictures of the kidneys and can show the disease in more detail. A renal biopsy may also be carried out, where a sample of kidney tissue is taken using a needle inserted through the skin into the kidney. The sample is then studied under a microscope and can give a more detailed indication of the problem.

Treatment of Renal Disease

Diet: The waste and excess water come from the food and drink we consume. Therefore, modifying the types and quantities of food eaten and limiting the amount a person drinks can help to reduce the build up of waste and extra water in the body. This can also delay the need for further treatment. Nutrients that may need altered through changes in diet include salt, proteins, potassium, phosphate and water. Energy intake may need adjusting in order to maintain a healthy body weight.

7 An Introduction to Renal Disease (Including Renal Failure)

The type of diet suggested will vary for each person depending on appetite, stage of the kidney disease and the results of blood tests.

Medication: Different types of drug can also help to reduce the build up of certain wastes and extra water in the body. Some drugs help to maintain the balance of chemicals in the body. Diuretics may be taken to help control the amount of water in the body.

When renal failure occurs the kidneys are not able to produce their hormones effectively and it can cause problems such as high blood pressure, anaemia and the weakening of bones. Drugs may be taken to prevent or treat these problems.

Dialysis: Once a person's kidneys stop working completely, they will need either dialysis or a kidney transplant to stay alive. Dialysis replaces the function of the kidneys, and acts as a filter to remove waste and extra water from the blood. There are two types of dialysis: haemodialysis and peritoneal dialysis. The choice of dialysis depends on many factors and different treatments suit different people. For most people with end stage renal failure dialysis is a long-term treatment and must be combined with a special diet and medication to be effective. Dialysis cannot replace the hormones normally produced by the kidneys. The lack of one of these hormones, erythropoietin (EPO), results in anaemia but it can now be given by injection to prevent the symptoms of severe anaemia such as fatigue and breathlessness.

Haemodialysis: Blood is pumped through tubes to a dialysis machine that filters away the waste and extra fluid. The cleansed blood is then returned to the body though another set of tubes. Regular and easy access to the bloodstream is needed for haemodialysis. This is done in a surgical operation to create an enlarged blood vessel called a fistula, usually in the forearm, into which the needles are inserted for dialysis. Haemodialysis usually takes place at a hospital renal unit, or a 'satellite' dialysis unit, three times a week usually for at least four hours. While having dialysis, the patient can do activities that do not require getting up and moving around, such as reading, sleeping or watching TV.

Peritoneal Dialysis: This type of dialysis cleans the blood inside the body using the lining of the abdominal cavity as a filter. Solution (dialysate) is put into the abdominal cavity through a tube called a catheter. It then absorbs the waste and excess water from the blood through the peritoneal membrane. After a few hours the used solution is drained away and replaced with fresh solution.

Patients carry out this procedure themselves at home. The catheter gives permanent access to the abdominal cavity. Surgery is needed to insert it into the abdomen. Part of the catheter stays permanently on the outside of the body to allow the solution to be drained in and out of the body. *Continuous ambulatory peritoneal dialysis (CAPD)* is the most common form of peritoneal dialysis. The solution is usually changed four times a day and takes 30-40 minutes each time. *Automated peritoneal dialysis (APD)* uses a machine to change the solution at night while the patient is asleep.

Sometimes a person on peritoneal dialysis can get peritonitis, an infection in the abdominal cavity. Peritonitis occurs if bacteria enter the fluid in the abdominal cavity either by contamination or from an existing infection. It can be treated using antibiotics. If peritonitis is very severe or occurs several times in a row, the doctor may need to replace the catheter. In this case, haemodialysis is needed until peritoneal dialysis is resumed.

Transplantation: Kidney transplantation is another form of treatment for end stage renal failure and is where the surgeon places a healthy, donated kidney into the patient's abdomen. If successful, the new kidney will take over the functions of the failed kidneys. Dialysis is no longer required and a normal and active life can be resumed. However, there is a risk that the body may try to reject the 'foreign' kidney. The patient must therefore take medication known as immunosuppressives each day to reduce this risk.

Not everyone is medically suitable for a transplant. Therefore, each patient must be carefully assessed before being placed on the waiting list. The waiting list is not like a queue. There are not enough donor kidneys for everyone so when a kidney does become available it is important that it is allocated so that it is as successful as possible. Research shows that the most successful transplants are when the kidney is allocated to a patient who has the same blood group as the donor kidney and is a close tissue match. The better the match, the less likely it is that the recipient's body will reject it. The donor kidney is therefore allocated to the patient who has the best match. A national system of kidney allocation is in place and kidneys are sent all over the country so that they can be allocated to the most suitable recipients.

If a transplanted kidney is rejected, dialysis treatment is once again needed. An unsuccessful transplant may not stop the patient from having another transplant, but it may become more difficult to match the patient to another kidney.

Donated kidneys can come from either living or cadaver donors. The best transplants come from living donors, particularly close relatives, though in some cases the donor is a spouse or partner.

Regular Medical Check-Ups

People with renal disease require regular check-ups to ensure that the waste and extra water are not building up in the blood, and to review their treatment. If there is a build up of waste and extra water, treatment can be adjusted. Access to a multidisciplinary team is essential to ensure that all aspects of the patient's care are addressed.

Renal Disease in Scotland

In the year 2000, 565 people started long-term renal replacement therapy by dialysis or transplantation in Scotland. Renal failure and its treatment impacts greatly on a patient's life and work. Although no cure exists for renal failure, there is much that can be done to improve outcomes and quality of life for patients. The risk of complications can be reduced by treatment that is both well managed and regularly assessed by a multidisciplinary team, while provision of appropriate information and discussion of treatment options can do much to prepare patients for future treatment.

In Scotland, transportation for haemodialysis remains an issue. For those living in rural areas, dialysis days can be very long due to the need to travel long distances to the nearest renal or satellite dialysis unit. The only way to reduce the need for dialysis is to increase the number of transplants. However, the shortage of kidneys available for transplantation is also an issue. The UK has one of the lowest cadaver donor rates in Europe. Scottish Executive figures estimate that if the number of transplants carried out remains constant for the next few years, the need for hospital haemodialysis could increase by a further 60%. While the standard of care for renal patients has improved in Scotland over recent years, there is still much to do and issues to be addressed. The clinical standards that follow are designed to support this process.

8 Evidence Base for the Clinical Standards for Adult Renal Services

There is a long history of audit of Renal Services in Scotland, initially through the European Dialysis and Transplant Association Registry established by a group of far-seeing European nephrologists in 1964. This registry collected data on the numbers of patients on renal replacement therapy in the majority of European countries and on any changes in the type of treatment as well as their outcome. Comparisons were possible between countries and between treatments providing invaluable information for research, management and planning purposes.

During the 1980s the rapid increase in the numbers of patients on renal replacement therapy made central collection of information impractical leading to the formation of national registries to collect data more locally. The development of these national registries such as the Scottish Renal Registry has allowed the more detailed collection of data to develop the evidence base for the creation of standards. Research, both in this country and abroad, has also been an important element in helping to create evidence-based standards.

Professor Sir Netar Mallick, when he was President of the Renal Association, established a sub-committee under the chairmanship of Dr Ram Gokal to prepare recommended standards and audit measures for the treatment of adult patients with renal failure. This sub-committee reviewed the evidence for guidelines in clinical nephrology and published, in conjunction with the Royal College of Physicians, the first edition of the standards document in April 1995. An extended second edition was published in November 1997 under the chairmanship of Professor Stewart Cameron. A further revision was published in 2002 under the direction of Professor Alison MacLeod. These evidence-based standards cover most aspects of clinical nephrology and are the principal sources for the standards for Renal Services set out by the CSBS.

In a similar way data on numbers and results of renal transplantation have been collected by the United Kingdom Transplant Service allowing the British Transplantation Society to recommend standards for Organ and Tissue Transplantation in the United Kingdom in 1998. Some of these standards for transplantation have also been adopted by the CSBS.

The Renal Association and the British Transplantation Society, along with other interested groups including those representing patients combined to form the Kidney Alliance, which has produced a Shadow National Framework for planning

and delivery of renal services. Recommendations from this group have also been referenced.

Standards for the care of renal patients produced by representative groups of dieticians and pharmacists have also been incorporated into the CSBS standards for renal services to produce as broad an evidence base as possible. Further details can be obtained by reference to the individual documents listed below.

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9 Clinical Standards for Adult Renal Services

STANDARD 1 – Clinical Management/Treatment 1: Haemodialysis
STANDARD 2 – Clinical Management/Treatment 2: Peritoneal Dialysis
STANDARD 3 – Clinical Management/Treatment 3: Haemoglobin in Patients on Dialysis
STANDARD 4 – Clinical Management/Treatment 4: Dialysis Access
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STANDARD 14 – Audit: Information/Data Collection

STANDARD 1 - Clinical Management/Treatment 1: Haemodialysis

Standard Statement Rationale

All people on haemodialysis achieve the Renal Association targets set for adequacy. There is regular audit of haemodialysis adequacy (see Standard 14).

Evidence from controlled trials and prospective studies demonstrate the benefits to all patients of adequate removal of low molecular weight toxins of which urea is an indicator.

- Treatment of Adults and Children with Renal Failure –Standards and Audit Measures, 3rd edition: Royal College of Physicians of London and Renal Association (2002).
- The Urea Reduction Ratio and Serum Albumin Concentration as Predictors of Mortality in Patients Undergoing Hameodialysis: Owen et al. *The New England Journal of Medicine* (1993); 329 (14): 1001-1006.
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Criteria

Essential

The following is demonstrated:

- 1. The target for haemodialysis adequacy is a Urea Reduction Ratio not less than 65% or stable Kt/V not less than 1.2 (dialysis and residual renal function) for thrice weekly dialysis. This is achieved in a minimum of 85% of patients. Where Kt/V is measured, the method used to calculate is documented.
- 2. Reasons for patients not achieving the target haemodialysis adequacy are documented and appropriate action taken.
- 3. Haemodialysis is offered thrice weekly unless there are specific circumstances.
- 4. Quality of water for dialysis and/or dialysis fluid is monitored monthly and meets Renal Association targets for microbial count.
- 5. The percentage of patients achieving the Renal Association standards for pre-dialysis potassium, phosphate, and calcium is calculated at a minimum of three monthly intervals.

STANDARD 2 - Clinical Management/Treatment 2: Peritoneal Dialysis

Standard Statement

All people on peritoneal dialysis achieve the Renal Association targets set for adequacy. There is regular audit of peritoneal dialysis adequacy (see Standard 14). There is safe and effective management in place for prevention of peritonitis.

Rationale

Evidence from prospective studies demonstrate that peritoneal dialysis adequacy is a predictor of outcome in patients on peritoneal dialysis.

Peritonitis is a serious complication of peritoneal dialysis.

 Treatment of Adults and Children with Renal Failure –Standards and Audit Measures, 3rd edition: Royal College of Physicians of London and Renal Association (2002).

Criteria

Essential

The following is demonstrated:

- 1. The target for peritoneal dialysis adequacy is a total weekly creatinine clearance (dialysis and residual renal function) not less than 50 l/week/1.73m² and/or weekly urea Kt/V exceeds 1.7 by 8 weeks after beginning peritoneal dialysis. This is maintained in a minimum of 85% of patients.
- 2. Reasons for patients not achieving the target peritoneal dialysis adequacy are documented, and appropriate action taken.
- 3. The percentage of patients achieving the Renal Association Standards for potassium, phosphate and calcium is calculated at a minimum of three monthly intervals.
- 4. The use of disconnect systems is standard unless contra-indicated.
- 5. Peritonitis rates are not more than one episode/18 patient-months.

STANDARD 3 – Clinical Management/Treatment 3: Haemoglobin in Patients on Dialysis

Standard Statement

All people on haemodialysis or peritoneal dialysis achieve targets set for haemoglobin levels after three months of dialysis. Transfusion is avoided wherever possible.

Rationale

Evidence from controlled trials demonstrates the benefits to all patients of appropriate haemoglobin concentration.

Repeated blood transfusions can maintain a haemoglobin but may make it more difficult to achieve future successful transplantation. They may also increase the risk of transmitting viral infections and cause iron overload.

- Treatment of Adults and Children with Renal Failure –Standards and Audit Measures, 3rd edition: Royal College of Physicians of London and Renal Association (2002).
- End Stage Kidney Failure: The Kidney Alliance (Jan 2001).

Criteria

Essential

- 1. The target is a haemoglobin concentration not less than 10g/dl (haematocrit is not less than 30%) after three months of dialysis. This is achieved in a minimum of 85% of patients.
- 2. Reasons for patients not achieving the target haemoglobin are documented, and appropriate action taken.
- 3. Iron status is monitored at a minimum of six-month intervals.
- 4. The number of patients receiving blood transfusions is monitored.

STANDARD 4 - Clinical Management/Treatment 4: Dialysis Access

Standard Statement	Rationale
All people requiring dialysis have timely surgery for access.	Access to the bloodstream or peritoneal cavity is the major factor in the success or failure of dialysis. Timely operations reduce the need for emergency procedures in planned patients. • Treatment of Adults and Children with Renal Failure –Standards and Audit Measures, 3rd edition: Royal College of Physicians of London and Renal Association (2002). • End Stage Renal Failure: The Kidney Alliance (Jan 2001).

Essential

- 1. Permanent access is available at the first dialysis in a minimum of 60% of patients who present at the renal service more than three months before requiring dialysis.
- 2. Reasons for patients not having permanent access available at their first dialysis are documented.
- 3. There are adequate dedicated theatre sessions (Reference Guideline: one weekly theatre session per 120 patients (approximately) on dialysis National Service Standard 3).

Desirable

- 4. A minimum of 70% of patients have arteriovenous fistulae or vein graft as their permanent haemodialysis access.
- 5. Permanent catheters are used as haemodialysis access in a maximum of 20% of patients.

STANDARD 5 - Clinical Management/Treatment 5: Nutritional

Status

Rationale

All patients receiving dialysis or with low creatinine clearance have nutritional status regularly assessed, evaluated and documented.

Standard Statement

Malnutrition is common in renal patients. Dietary intervention and frequent review of patients can prevent or treat malnutrition. It may also delay the progression of renal disease and

• Renal Nutrition Group Standards for Adult Patients Over 18 Years Old: Renal Nutrition Group Working Party of the British Dietetic Association (1998).

can improve or maintain quality of life.

- Treatment of Adults and Children with Renal Failure - Standards and Audit Measures, 3rd edition: Royal College of Physicians of London and Renal Association (2002).
- Clinical Practice Guidelines for Nutrition in Chronic Renal Failure: National Kidney Foundation (June 2000).

Essential

- 1. All patients are assessed at least six-monthly to identify those at risk of malnutrition.
- 2. Patients identified as at risk have nutritional goals set, documented and monitored in accordance with Renal Nutritional Group Standards.
- 3. Reasons why patients identified as at risk do not achieve nutritional goals are documented, and appropriate action taken.
- 4. There is a designated dietician with a recognised postgraduate qualification and/or renal experience.

Desirable

5. Baseline anthropometry is documented for all patients at the beginning of dietetic treatment by an individual trained in the technique.

STANDARD 6 – Clinical Management/Treatment 6: Drug Therapy

Standard Statement

All people with chronic renal failure or on renal replacement therapy receive appropriate drug therapy and advice on their medicines.

Rationale

Care delivered in accordance with evidencebased clinical guidelines, protocols and good practice guidelines produces better outcomes for patients.

Individual dosage adjustment is a key requirement for efficacy and safety in patients with chronic renal failure.

Appropriate education/counselling for patients regarding their medicines can encourage participation in recommended treatment, thereby improving outcomes.

- Clinical Pharmacy in the Hospital
 Pharmaceutical Service: A Framework for
 Practice: Clinical Resource and Audit Group
 (CRAG) Steering Group and Working Group
 (1996).
- Treatment of Adults and Children with Renal Failure –Standards and Audit Measures, 3rd edition: Royal College of Physicians of London and Renal Association (2002).

- 1a. There are protocols for:
 - Management of anaemia.
 - Treatment of peritonitis.
 - Immunisation for Hepatitis B.
- 1b. In addition, for transplant units there are protocols for:
 - Immunosuppressive regimens.
 - Cytomegalovirus and pneumocystis infection prophylaxis.
 - Renal vein thrombosis prophylaxis.
 - Management of delayed graft function.
- 2. All patients' prescriptions are reviewed to ensure their drug therapy is appropriate for their circumstances.
- 3. Information and advice about the use of drugs in chronic renal failure or in dialysis patients is available to healthcare professionals and renal patients.
- 4. There is a designated pharmacist with a recognised postgraduate qualification and/or renal experience.

STANDARD 7 - Clinical Management/Treatment 7: Access to Multidisciplinary Team

All people with end stage renal failure have access to a multidisciplinary team. Patients with end stage renal failure have complex needs, which cannot be addressed by a single specialty. • End Stage Renal Failure: The Kidney Alliance (Jan 2001). • Renal Nutrition Group Standards for Adult Patients Over 18 Years Old: Renal Nutrition Group Working Party of the British Dietetic Association (1998).

- 1. In addition to the regular medical and nursing staff, patients are referred to the following services when required:
 - physiotherapy;
 - pharmacy;
 - dietetics;
 - occupational therapy;
 - designated social worker with a recognised postgraduate qualification and/or renal experience;
 - primary healthcare team;
 - community hospitals (where applicable);
 - transplant co-ordinator/ liaison nurse;
 - counselling service;
 - clinical psychology;
 - liaison psychiatry.
- 2. Dialysis patients are regularly and confidentially reviewed by a multidisciplinary team including medical and nursing staff, dieticians and pharmacists.

STANDARD 8 – Transplantation 1: Assessment for Transplantation

Standard Statement	Rationale
All dialysis patients are assessed for suitability of transplantation within three months of starting dialysis.	The assessment of patients for transplantation identifies those who would benefit from this treatment.
	• Treatment of Adults and Children with Renal Failure –Standards and Audit Measures, 3rd edition: Royal College of Physicians of London and Renal Association (2002).
	• End Stage Renal Failure: The Kidney Alliance (Jan 2001).
	• UK Guidelines for Living Donor Kidney Transplantation: Working Party of the British Transplantation Society (BTS) and The Renal Association (2000).
	• Towards Standards for Organ and Tissue Transplantation in the UK: British Transplantation Society (BTS) (1998).
	 Donor Organ Sharing Scheme: Operating Principles for Renal Transplant Units in the UK: United Kingdom Transplant Support Service Authority Users' Kidney Advisory Group (UKTSSA) (1999).

Essential

The following is demonstrated:

- 1. All patients are assessed for transplantation within three months of starting dialysis and those suitable are referred to a Transplant Centre.
- 2. Patients referred are seen by a nephrologist and surgeon from the Transplant Centre.
- 3. Decisions regarding the patient's assessment at the Transplant Centre are communicated in writing, to the patient, the GP and, where appropriate, the carer.
- 4. All patients on dialysis are reviewed annually for their suitability for transplantation.
- 5. All patients on the waiting list are informed of the outcome of their annual review either orally or in writing.
- 6. The percentage of dialysis patients on the waiting list for transplantation is monitored and reviewed annually.
- 7. The unit takes part in the Renal Donor Scheme operated by UK Transplant.
- 8. Type 1 diabetic patients with renal failure are considered for combined pancreas and kidney transplant.

STANDARD 9 – Transplantation 2: Kidney Retrieval

Standard Statement	Rationale
	The quality of retrieved organs has an impact on the outcome of transplantation. • Towards Standards for Organ and Tissue Transplantation in the UK: British Transplantation Society (BTS) (1998). • Donor Organ Sharing Scheme: Operating Principles for Renal Transplant Units in the UK: United Kingdom Transplant Support Service Authority Users' Kidney Advisory Group (UKTSSA) (1999). • Treatment of Adults and Children with Renal Failure –Standards and Audit Measures, 3rd edition: Royal College of Physicians of London and Renal Association (2002).

- 1. Kidneys are retrieved by a transplant surgeon experienced in the procedure.
- 2. Cold storage time is below 24 hours, where possible.
- 3. Reasons for cold storage exceeding 24 hours are documented.
- 4. Documentation of damage to retrieved kidneys is sent with the donor kidney to the transplant unit.
- 5. A minimum of 70% of donor kidneys from people on artificial ventilation, who are confirmed to be dead by brain stem testing, function immediately.
- 6. The percentage of kidneys that never function is no more than 5% for people on artificial ventilation, who are confirmed to be dead by brain stem testing.

STANDARD 10 – Transplantation 3: Survival Rates

Standard Statement	Rationale
Patient and transplant survival rates following kidney transplantation are within acceptable limits.	Patient and transplant survival rates after transplantation are measures of the quality of assessment of suitability for transplantation, matching of donor kidneys to the recipient and subsequent management.
	• UK Guidelines for Living Donor Kidney Transplantation: Working Party of the British Transplantation Society (BTS) and The Renal Association (2000).
	 Towards Standards for Organ and Tissue Transplantation in the UK: British Transplantation Society (BTS) (1998).
	• Treatment of Adults and Children with Renal Failure –Standards and Audit Measures, 3rd edition: Royal College of Physicians of London and Renal Association (2002).
	• Renal Transplant Audit 1990-1999: UK Transplant (Dec 2001).

- 1. Following live related donor kidney transplantation:
 - Patient survival rate is a minimum of 95% at 1 year.
 - Transplant survival rate is a minimum of 93% at 1 year.
- 2. Following first cadaver kidney graft transplantation:
 - Patient survival rate is a minimum of 95% at 1 year and a minimum of 80% at 5 years.
 - Transplant survival rate is a minimum of 85% at 1 year and a minimum of 66% at 5 years.
- 3. Transplant patients are reviewed regularly by a nephrologist or transplant surgeon.

STANDARD 11 – Patient Focus 1: Out-patients

Rationale
Protracted waiting times cause distress and anxiety for patients and their families and increase the potential for deterioration in condition.
• End Stage Renal Failure: The Kidney Alliance (Jan 2001).

- 1. New patients are offered an appointment to be seen within one month of referral.
- 2. Clinic letters are sent to the GP within two weeks of being seen by a nephrologist.
- 3. Changes in medication are communicated to the GP via the patient using a written note or by updating a drug booklet.

STANDARD 12 – Patient Focus 2: Provision of Patient Information

All people with chronic renal failure or on renal replacement therapy, and carers where appropriate, are given information to help them make informed choices. Information helps patients make informed choices, which can reduce anxiety and encourage participation in recommended treatment. Generic Standards: Clinical Standards Board for Scotland (2001). End Stage Renal Failure: The Kidney Alliance (Jan 2001).

Essential

- 1. All people diagnosed with chronic renal failure, and carers where appropriate, are provided with appropriate information materials which are evidence-based, identify treatment options, possible outcomes, risks, possible side-effects, and sources of further information.
- 2. Medical and nursing staff discuss possible treatment options which may include home and hospital dialysis, CAPD and APD, cadaver and live donor transplantation, with patients, and carers where appropriate, at a dedicated appointment or home visit.
- 3. Patients, and carers where appropriate, are involved in decisions about treatment and changes in treatment.

Desirable

4. There is a designated pre-dialysis nurse specialist.

STANDARD 13 – Patient Focus 3: Transportation for Haemodialysis

Standard Statement	Rationale
Delays for patients attending for dialysis are minimised through reasonable measures taken by the Trust.	Length of the dialysis day is very important to patients attending hospital for haemodialysis thrice weekly. Reducing the length of the day helps to minimise the disruption to daily life caused by an already physically demanding and time-consuming form of treatment. • End Stage Renal Failure: The Kidney Alliance (Jan 2001). • Haemodialysis in a Rural Area: A Demanding Form of Treatment: Health Bulletin 59(5) Sept 2001.

Essential

- 1. 50% of all patients using hospital transportation are collected from home within half an hour of their allotted pick-up time, and all are collected within one hour.
- 2. 50% of all patients begin dialysis within half an hour of appointment time, and all begin within one hour.
- 3. 50% of all patients using hospital transportation are collected within half an hour of the end of dialysis, and all are collected within one hour, provided they are clinically fit.
- 4. Reasons for delays of more than an hour are documented.
- 5. Patients who wait for hospital transport do so in comfortable surroundings.

Desirable

6. Within the constraints of population density and geography, a unit is available within half an hour's travelling time for patients.

STANDARD 14 – Audit: Information/Data Collection

Standard Statement	Rationale
There is continuous data collection to facilitate regular national audit through the Scottish Renal Registry.	The review of clinical practice through audit is a well-established means of promoting the quality of clinical care by identifying shortfalls in performance against standards and best practice. • Generic Standards: Clinical Standards Board for Scotland (2001). • SIGN Guideline 1: Clinical Guidelines: Criteria for Appraisal for National Use (1995).

Essential

- 1. There are information systems in place for continuous collection of the Scottish Renal Registry core data set to facilitate audit.
- 2. The unit takes part in comparative audits of dialysis and transplantation through the Scottish Renal Registry and, where appropriate, UK Transplant.
- 3. There is data collection of the following, where appropriate, to facilitate regular audit:
 - Haemodialysis adequacy (monthly for hospital dialysis and every three months for home dialysis).
 - Peritoneal dialysis adequacy (six monthly).
 - Haemoglobin levels (monthly for hospital dialysis and every three months for peritoneal and home dialysis).
 - Peritonitis (occurrence, investigation, treatment and cause).
 - Type and time of access surgery.
 - Immediate function of cadaver kidneys.
 - Patient and transplant survival rates.

Desirable

4. There is collection of incidence, management and outcome data on acute renal failure.

10 Glossary of Terms

Term Definition		
access	Entry to the blood stream for haemodialysis or entry to the abdominal cavity for peritoneal dialysis.	
accreditation	A process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.	
acute renal failure	The rapid loss of kidney function over a few hours or days.	
acute sector	Hospital-based health services which are provided on an in-patient or outpatient basis.	
adequacy	Refers to how well dialysis replaces the function of the kidneys.	
allocation	The matching of an organ to a patient based on blood and tissue type.	
anaemia	A reduction in the quantity of the haemoglobin in the blood. The main symptoms are excessive tiredness, breathlessness on exertion, pallor and poor resistance to infection.	
anthropometry	The measuring of the human body or part of the human body.	
antibiotic	A chemical substance produced synthetically or by a microorganism which has the capacity to inhibit the growth of or to kill other microorganisms.	
APD	See automated peritoneal dialysis.	
arteries	Blood vessels which carry blood away from the heart to supply the tissues.	
arteriovenous fistula	A connection between an artery and a vein (this excludes arteriovenous grafts using artificial vessels).	
assessment	The process of measuring the quality of an activity, service or organisation.	
assessment (for transplantation)	The physical examination, tests and studies required to check whether a person is suitable to receive an organ transplant.	
audit	A process which allows for the systematic and critical analysis of the quality of care.	
automated peritoneal dialysis	A form of peritoneal dialysis that requires a machine to control the movement of fluid into and out of the peritoneal cavity. APD is carried out at home each night while the patient sleeps.	
biochemical	Relating to the chemistry of the body.	
biopsy	The removal of a small piece of tissue from an organ or part of the body for histological analysis, microscopic study, or pathologic evaluation.	

blood pressure	Blood pressure is related to the force of the heart pumping and the resistance to the flow of blood through the body. It is the pressure of the blood in the main arteries needed to push it through the smaller vessels of the circulation.	
blood transfusion	The infusion of a volume of blood obtained from a healthy person into the bloodstream of a patient whose blood is deficient in quantity or quality, through accident or disease.	
brain stem testing	A set of specific tests carried out by doctors to confirm death.	
BTS	British Transplantation Society.	
cadaver kidney	A kidney that has been donated by a previously healthy person who has died suddenly. Kidneys for donation are usually removed when the donor's death has been confirmed by brain stem testing but the heart is still beating due to artificial ventilation.	
calcium	A chemical element obtained through diet that is essential in the formation of bones and teeth.	
CAPD	See continuous ambulatory peritoneal dialysis.	
care plan	A document which details the care and treatment that a patient/user receives and identifies who delivers the care and treatment.	
carer	A person who looks after family, partners or friends in need of help because they are ill, frail, or have a disability. The care they provide is unpaid.	
catheter	A hollow tube used to transport fluids to or from the body.	
chronic	Present over a long period of time.	
chronic renal failure	The slow and progressive deterioration of kidney function.	
clinical governance	A framework through which NHS organisations are accountable for both continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish.	
Clinical Resource and Audit Group	The lead body within the Scottish Executive Health Department promoting clinical effectiveness in Scotland. The main committee, together with its subcommittees provides advice to the Health Department, acts as a national forum to support and facilitate the implementation of the clinical effectiveness agenda and funds a number of clinical effectiveness programmes and projects. Abbreviated as CRAG. Website address: www.show.scot.nhs.uk/crag/	

clinical service	Service provided by health care professionals.	
Clinical Standards Board for Scotland	The Clinical Standards Board for Scotland is a statutory body, established as a special NHS Board in April 1999. Its role, in line with the Scottish Executive's commitment to quality, openness and public accountability, is to promote public confidence that the services provided by the NHS are safe and that they meet nationally agreed standards, and to demonstrate that, within the resources available, the NHS is delivering the highest possible standards of care. Abreviated as CSBS.	
clinical trial	Research study conducted with patients, usually to evaluate a new treatment or drug. Each trial is designed to answer scientific questions and to find better ways to treat individuals with a specific disease.	
cold storage	The process that allows an organ to be kept cold in sterile conditions until it reaches the operating theatre.	
community hospital	A local hospital, unit or centre providing an appropriate range and format of accessible health care facilities and resources. These will include in-patient and may include out-patient, diagnostic, day care, primary care and outreach services for patients provided by multidisciplinary teams. Medical care is normally led by general practitioners.	
computerised tomography (CT)	An X-ray imaging technique used in diagnosis that can reveal many soft tissue structures not shown by conventional radiography.	
conservative management	The treatment of renal failure without dialysis.	
continuous ambulatory peritoneal dialysis	A form of peritoneal dialysis in which dialysis fluid is exchanged at regular intervals throughout the day.	
contra-indication	Any condition, past or present, which makes a particular line of treatment unsuitable or undesirable.	
controlled trials	Studies in which treatments are compared – these may include inactive or placebo therapy.	
core data set	A minimal set of information related to a specific medical condition – includes demographic, clinical management and outcome data.	
CRAG	See Clinical Resource and Audit Group.	
creatinine	A waste product that is removed from the body by the kidneys, and excreted in the urine. A high level of creatinine in the blood indicates kidney damage.	

creatinine clearance	A measure used by hospital staff to assess how well the kidneys are working or whether enough dialysis is being provided.
criterion/criteria	Criterion is the term used for the singular. We have one criterion, and several criteria. Criteria provide the more detailed and practical information on how to achieve a standard and can be described as structure, process and outcome criteria.
CSBS	See Clinical Standards Board for Scotland.
СТ	See computerised tomography.
cytomegalovirus	A virus that can cause severe infections in patients who have recently had a renal transplant.
data set	A list of required and specific information.
data source	The source of evidence to demonstrate whether a standard or criterion is being met.
delayed graft function	A kidney transplant that does not work immediately.
desirable (criterion/criteria)	Good practice that is being achieved in some parts of the service and demonstrates levels of quality to which other providers of a similar service should strive.
diabetes	A disorder characterised by high levels of glucose (sugar) in the bloodstream.
diabetic nephropathy	Kidney disease that has developed as a result of diabetes.
diagnosis	Identification of an illness by means of its signs and symptoms. This involves ruling out other illnesses and causal factors for the symptoms.
dialysate	A sterile fluid used in dialysis to facilitate the extraction of waste from the blood.
dialysis	A treatment for kidney failure that removes wastes and water from the blood artificially.
dialysis fluid	See dialysate.
dietary assessment	An evaluation of the extent to which dietary intake is likely to meet nutritional needs. Factors assessed include current food and fluid intake, duration and severity of any changes in appetite and oral intake, and the presence of factors which may be affecting food and fluid intake.
dietician	An expert in nutrition who helps people with special health needs plan the kinds and amount of foods to eat.

discharge	A discharge marks the end of an episode of care. Types of discharge are in-patient discharge, day-case discharge, day-patient discharge, out-patient discharge and PAM discharge.
disconnect systems	A peritoneal dialysis system in which the dialysis bag is not connected to the patient between exchanges.
diuretic	A drug that increases the flow of urine.
donor	Someone who gives blood or an organ from their body to be used in another person's body (the recipient).
end stage renal failure	Kidney failure requiring treatment by dialysis or kidney transplantation.
erythropoietin (EPO)	A substance normally produced by the kidneys which stimulates the bone marrow to produce red blood cells. In renal failure less is formed resulting in anaemia, but it can be replaced by an injection of artificially produced erythropoietin.
essential (criterion/criteria)	A criterion that should be met wherever a service is provided.
European Dialysis and Transplant Association Registry	A registry of patients on renal replacement therapy throughout Europe organised by the professional body for European nephrologists.
evaluation	The study of the performance of a service (or element of treatment and care) with the aim of identifying successful and problem areas of activity.
evidence-based	The process of systematically finding, appraising, and using contemporaneous research findings as the basis for clinical decisions.
fistula	See arteriovenous fistula.
function	The activity of an organ or part of the body.
generic standards	Standards that apply to most, if not all, clinical services.
genetic disorder	An illness or condition that has been inherited.
glomerulonephritis	The inflammation of the filtering units in the kidneys which alters their normal functions.
glomerulus	One of the tiny filtering units of the kidneys. Each kidney contains about one million glomeruli.
GP	General Practitioner.
graft	A transplanted organ or tissue.

guideline	Systematically developed statements which assist in decision-making about appropriate healthcare for specific clinical conditions.
haematocrit	The ratio of the volume of red blood cells to the total volume of blood.
haematological	Relating to the blood.
haemodialysis	A treatment for kidney failure in which blood is purified by passing it across an artificial membrane to remove waste products.
haemoglobin	The part of red blood cells that carries oxygen around the body.
HDL	See Health Department Letter.
Health Council	Each NHS Board area has a Health Council, an organisation whose aim is to promote public consultation and participation in health-related matters. Sometimes referred to as a Local Health Council.
Health Department Letter	Health Department Letter (formerly known as Management Executive Letters - MELs), formal communications from the Scottish Executive Health Department to NHSScotland.
healthcare professional	A person qualified in a health discipline.
home dialysis	Dialysis that is carried out at home rather than in hospital.
hospital dialysis	Dialysis that is carried out in a hospital renal unit.
hospital transportation	Hospital vehicles that are used to transport patients to and from hospital for treatment.
immediate function	A kidney transplant that works immediately.
immunosuppressive drug	A drug that suppresses the immune system of a patient in order to allow that patient to accept a transplant.
incidence	How often a disease occurs; the number of new cases of a disease among a certain group of people for a certain period of time.
iron	A key component of haemoglobin. When red blood cells are lost, so is iron.
Island NHS Board	Island NHS Boards do the work of both Boards and Trusts in that they have a strategic and operational role. There are three Island NHS Boards, covering Shetland, Orkney, and the Western Isles.
kidney	One of two bean-shaped organs located near the middle of the back just under the ribcage. Kidneys filter waste from the blood, remove excess water from the body, maintain the proper balance of salts and acids in the body, and produce essential hormones.

Kidney Alliance	An 'umbrella' body representing all organisations involved in renal services.
Kidney Patients' Association	A group or society whose aim is to support kidney patients and their carers.
Kt/v	A calculation used by hospital staff to assess the adequacy of dialysis.
LHCC	See Local Health Care Co-operative.
liaison psychiatry	Services provided for the diagnosis, care and prevention of mental illnesses.
live donor	Someone who agrees to give one of their organs during life to another person.
Local Health Care Co-operative	A grouping of general medical practices.
malnutrition	Insufficient nutrition or the wrong sort of nutrition.
Management Executive Letter	Formal communications from the Scottish Executive Health Department to NHSScotland, now known as Health Department Letters (HDLs). Abbreviated as MEL.
matching	The process by which a suitable kidney is found for transplantation.
medication	Drugs prescribed to treat a condition.
MEL	See Management Executive Letter.
microbial count	Relating to micro-organisms or germs.
molecular weight	A term used to describe the weight or mass of chemical compounds.
monitoring	The systematic process of collecting information on clinical and non-clinical performance. Monitoring may be intermittent or continuous. It may also be undertaken in relation to specific incidents of concern or to check key performance areas.
multidisciplinary	A multidisciplinary team is a group of people from different disciplines (both healthcare and non-healthcare) who work together to provide care for patients with a particular condition. The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition, the scale of the service being provided and geographical/socio-economic factors in the local area.
National Service Standard	Standards that have been set by the Kidney Alliance. They form the core objectives of the strategic plan for renal services (2001–2006) that aims to ensure patients with end stage renal failure receive the best medical care.
nephritis	An inflammation of the kidneys.

nephrologist	A doctor who specialises in kidney disease.
nephrology	The branch of medical science that deals with the kidneys.
nephron	A term which refers to the million or so structures within each kidney that filter blood in order to make urine.
NHS Board	NHS Boards replaced the separate board structures of Health Boards and NHS Trusts. The NHS Boards cover the same geographical area as the old Health Boards. The overall purpose of NHS Boards is to ensure the efficient, effective and accountable governance of the local NHS system and to provide strategic leadership and direction for the system as a whole, focusing on agreed outcomes.
NHS Priorities	The three national clinical priorities remain: Mental Health; Coronary Heart Disease and Stroke; and Cancer. Source: Scottish Office Department of Health Chief Scientist Office Research Strategy for the National Health Service in Scotland (Revised 1998).
NHSScotland	The National Health Service in Scotland.
nutrient	That which nourishes.
nutrition	All foods, the physical and chemical process by which food is converted into body tissue or energy.
nutritional intake	Dietary intake of healthy or nourishing foods.
nutritional status	A term that describes the extent to which an individual's nutritional needs are being met.
occupational therapy	The treatment of mental and physical health problems by encouraging people to participate in specific activities that will help them to reach their maximum level of function and independence in all aspects of their daily life. An occupational therapist is a person specifically trained to provide such assessment and treatment.
organ	A part of the body that performs a particular function.
outcome	The end result of care and treatment. In other words, the change in health, functional ability, symptoms or situation of a person, which can be used to measure the effectiveness of care and treatment.
out-patient	A patient reviewed in a hospital but who does not need to be admitted to the hospital.
PAM	See professions allied to medicine.

patient	A person who is receiving care or medical treatment. A person who is registered with a doctor, dentist, or other healthcare professional, and is treated by him/her when necessary. Sometimes referred to as a user.
patient journey	The pathway taken through the NHS by the patient (the person who is receiving medical treatment), and as viewed by the patient.
patient survival rate	The number or proportion of patients who remain alive on renal replacement therapy during follow-up.
patient-month	A measure of follow-up which takes account of the number of patients treated and the time during which they have been observed.
PCRG	See Primary Care Reference Group.
PD	See peritoneal dialysis.
peer review	Review of a service by those with expertise and experience in that service, either as a provider, user or carer, but who are not involved in its provision in the area under review. In the CSBS approach all members of a review team are equal.
peritoneal cavity	The space in the abdomen that contains the intestines and other internal organs.
peritoneal dialysis	A treatment for kidney failure in which dialysis fluid is introduced into the peritoneal cavity to remove wastes and water from the blood.
peritonitis	Inflammation of the peritoneum (the lining of the abdominal cavity).
pharmacist	A qualified professional who understands the nature and effects of medicines and how they may be produced and used to prevent and treat illness, relieve symptoms or assist in the diagnosis of disease. Pharmacists use their expertise for the well-being and safety of users and the public.
phosphate	A mineral commonly found in food, especially dairy products, which binds to calcium to keep bones strong and healthy.
physiotherapy	The branch of treatment that employs physical methods to promote healing, including the use of light, infrared and ultraviolet rays, heat, electric current, massage, manipulation and remedial exercise.
planned patients	Patients for whom treatment or surgery is planned in advance.
pneumocystis infection	A severe form of pneumonia in patients who have recently had a renal transplant.

policy	An operational statement of intent in a given situation.
polycystic kidney disease	An inherited kidney disease in which cysts replace normal kidney tissue, causing the kidneys to fail.
postgraduate qualification	A degree or qualification that is awarded after a period of further training.
potassium	An essential mineral in the body found in many foods, especially fruit and vegetables. It is responsible for normal muscle function, including heart muscle, but excessively high levels in the blood can cause the heart to stop beating.
pre-dialysis	Before dialysis.
prescription	Usually a written recipe of treatment.
primary care	The conventional first point of contact between a patient and the NHS. This is the component of care delivered to patients outside hospitals and is typically, though by no means exclusively, delivered through general practices. Primary care services are the most frequently used of all services provided by the NHS.
Primary Care Reference Group	Established to help the CSBS ensure that the component of care delivered to patients outside hospitals is included in its standards, and to promote the accreditation of general practices. Abbreviated as PCRG.
primary healthcare team	The primary healthcare team encompasses a range of family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners.
professions allied to medicine	Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dieticians, etc. Abbreviated as PAM.
prophylaxis	The prevention of disease; preventive treatment.
prospective studies	Studies that are carried out from the present to the future.
protein	One of the three main classes of food. Proteins are made of amino acids, which are called the building blocks of the cells. The cells need proteins to grow and to mend themselves. Protein is found in many foods such as meat, fish, poultry and eggs.
protocol	A policy or strategy which defines appropriate action. Also covers the adoption, by all staff, of national or local guidelines to meet local requirements in a specified way, resulting in what are known as local protocols.

quality assurance	Improving performance and preventing problems through planned and systematic activities including documentation, training and review. Abbreviated as QA.
Quality Assurance Manual	CSBS document outlining the methods and procedures to be used in setting standards and reviewing services.
rationale	Scientific/objective reason for taking specific action.
recipient	A person who receives a new organ.
red blood cells	Cells in the bloodstream that contain haemoglobin which carries oxygen from the lungs to the tissues.
referral	The process whereby a patient is transferred from one professional to another, usually for specialist advice and/or treatment.
regimen	A course of treatment such as a prescribed combination of diet and drugs.
register	A collection of similar information from individuals to compile an overview observation.
renal	A term that means relating to the kidneys.
Renal Association	The Renal Association is the professional body for UK nephrologists. The Standards Subcommittee of the Renal Association has produced recommended standards and audit measures for the treatment of adult patients with renal failure. Where evidence or recommendations exist in the Renal Association standards for an area of renal services for which the CSBS is setting standards, it will be referenced.
renal failure	An abnormality resulting from the inability of the kidneys to function and resulting in a build-up of poisons in the body.
renal function	A measure of how well a person's kidneys are working to remove waste products from the body.
renal nutrition	Food and/or diet suitable for patients with kidney disease.
Renal Nutrition Group	A subgroup of the British Dietetic Association with special expertise in the nutritional aspects of renal failure.
renal replacement therapy	Treatment to replace the function of the kidneys in a person whose kidneys no longer work. Treatment is usually in the form of dialysis or transplant.
renal unit	The part of a hospital which specialises in the treatment of people with kidney failure.

renal vein	The blood vessel that returns filtered blood from the kidney to the rest of the circulation.
residual renal function	The remaining function of kidneys which are not working properly.
retrieval	A term used to describe the process by which organs are removed for the purposes of transplantation.
RRT	See renal replacement therapy.
Scottish Executive Health Department	The Scottish Executive Health Department is responsible for health policy and the administration of the National Health Service in Scotland. Abbreviated as SEHD.
Scottish Intercollegiate Guidelines Network	SIGN was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland, to sponsor and support the development of evidence-based clinical guidelines for NHSScotland. Where a SIGN guideline exists for a specialty or service for which CSBS is setting standards, it will be referenced. For further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed, contact: SIGN Secretariat, Royal College of Physicians, 9 Queen Street, Edinburgh EH2 1JQ. Abbreviated as SIGN. Website address: www.sign.ac.uk/
Scottish Renal Association	A group of healthcare professionals whose common purpose is to promote the highest standards of care for renal patients in Scotland.
Scottish Renal Registry	A national database which records the clinical details of renal patients throughout Scotland for audit purposes, and the clinicians who manage the Registry.
SEHD	Scottish Executive Health Department.
self-assessment	Assessment of performance against standards by individual clinical teams and/or Trusts providing the service to which the standards are related.
sensitise	The process by which repeated blood transfusions and previous transplants can reduce the likelihood of finding a compatible kidney in patients with renal failure.
SIGN	See Scottish Intercollegiate Guidelines Network.
SIGN guideline	Scottish Intercollegiate Guidelines Network guideline.
social work	Social work services provide advice and practical help for problems resulting from social circumstances. A social worker is a person who has obtained a professional qualification in social work. A social worker supports vulnerable people and their carers with the aim of enhancing the quality of all aspects of their daily lives.

standard statement	An overall statement of desired performance.
symptom	A reported feeling or observable physical sign of a person's condition that indicates a physical or mental abnormality.
therapy	A word often used to mean treatment.
thrombosis	The formation of a blood clot in an artery blocking the blood supply. For example, a clot in a coronary artery can cause a heart attack.
transplant	An organ or tissue that is transferred from one individual to another.
transplant co-ordinator	Someone who assists in co-ordinating organ retrieval and the necessary tests, studies and other activities to assess the suitability of a person to receive a transplantation.
transplant liaison nurse	A nurse working in a renal unit that does not offer transplantation, who liaises with the transplant co-ordinator to ensure that patients are referred for transplantation and have all the necessary tests before being accepted onto the transplant waiting list.
transplant surgeon	A doctor who specialises in performing operations to put an organ from one person (the donor) into another (the recipient).
transplant survival rate	The number or proportion of transplants which remain functional during follow-up.
transplantation	The act of transferring an organ or tissue from one individual to another.
Trust	A Trust is an NHS organisation responsible for providing a group of healthcare services for the local population. An Acute Hospital Trust provides hospital services. A Primary Care Trust delivers primary care/community health services. Mental health services (both hospital and community based) are now usually provided by Primary Care Trusts.
type 1 (insulin- dependent) diabetes	Type 1 diabetes develops if the body is unable to produce any insulin. This type of diabetes usually presents before the age of 40. It is treated by insulin injections and diet.
UK Transplant	A special health authority working within the NHS to support transplant units throughout the UK and in Northern Ireland.
ultrasound	Test that bounces sound waves off tissues and converts the echoes into pictures.
urea	A waste product which is formed when the body breaks down protein.

urea reduction ratio	A measurement (URR) used by hospital staff in haemodialysis to check that
	enough dialysis is being provided (dialysis adequacy).
URR	See urea reduction ratio.

Our Commitment

The Board will:

- involve NHS staff, patients and the public in all parts of its work;
- work with and support NHS staff in improving standards;
- assist NHSScotland in delivering the highest quality of NHS care to each patient;
- base its conclusions and recommendations on the best evidence available;
- be open and transparent in all its work through wide circulation of reports written in language that can be understood by all and is jargon free;
- seek to avoid duplication of effort through working closely with other national organisations involved in improving the quality of care within the NHS;
- ensure that its own work is subject to quality assurance and evaluation.



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